

Original Article

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Prevalence of specialised palliative care consultation for eligible children within a paediatric cardiac ICU

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Abstract

Objective: Retrospectively apply criteria from Center to Advance Palliative Care to a cohort of children treated in a cardiac ICU and compare children who received a palliative care consultation to those who were eligible for but did not receive one. *Methods:* Medical records of children admitted to a cardiac ICU between January 2014 and June 2017 were reviewed. Selected criteria include cardiac ICU length of stay >14 days and/or ≥ 3 hospitalisations within a 6-month period. *Measurements and Results:* A consultation occurred in 17% (n = 48) of 288 eligible children. Children who received a consult had longer cardiac ICU (27 days versus 17 days; p < 0.001) and hospital (91 days versus 35 days; p < 0.001) lengths of stay, more complex chronic conditions at the end of first hospitalisation (3 versus 1; p < 0.001) and the end of the study (4 vs. 2; p < 0.001), and higher mortality (42% versus 7%; p < 0.001) when compared with the non-consulted group. Of the 142 pre-natally diagnosed children, only one received a pre-natal consult and 23 received it post-natally. Children who received a consultation (n = 48) were almost 2 months of age at the time of the consult. *Conclusions:* Less than a quarter of eligible children received a consultation. The consultation usually occurred in the context of medical complexity, high risk of mortality, and at an older age, suggesting potential opportunities for more and earlier paediatric palliative care involvement in the cardiac ICU. Screening criteria to identify patients for a consultation may increase the use of palliative care services in the cardiac ICU.

In the past decade, Hospice and Palliative Care Medicine has rapidly expanded to the paediatric population with increasingly available programs in children's hospitals across the country.^{1–3}

Leading organisations, including the American Academy of Pediatrics and the Improving Palliative Care in the Intensive Care Unit Advisory Board, recommend paediatric palliative care involvement at the time of diagnosis of a potentially life-limiting condition and continuing throughout disease trajectory, regardless of the outcome.^{4,5}

The integration of palliative care into the medical management of children with heart disease is beneficial to children, families, and health care providers.^{6,7} Involvement of paediatric palliative care soon after diagnosis provides an extra layer of support to families throughout their child's heart disease course as the family faces many decisions regarding goals of care, interventions, quality of life, and advanced care planning. Paediatric palliative care involvement can help reduce symptoms of stress, anxiety, and depression for both the child and parents while improving parental coping, grieving, and bereavement outcomes.^{8–11} In addition to psychosocial and spiritual support for families and the patient, paediatric palliative care teams are adept at identifying and reducing pain and other physical symptoms.⁹ Health care providers are additional beneficiaries, as paediatric palliative care teams help facilitate multidisciplinary care conferences, assist with symptom management, and expertly facilitate sensitive conversations, including end-of-life care with families of critically ill children.^{11,12}

Despite the growing evidence that integration of paediatric palliative care into the management of critically-ill children is beneficial, the rates of paediatric palliative care consultation in children with heart disease in the cardiac ICU remain less than 10%.¹³ To facilitate and expedite paediatric palliative care consultation in the cardiac ICU, the Center to Advance Palliative Care published criteria to identify children with serious illness who would benefit from a palliative

care consultation. The criteria are divided into diagnoses within organ systems that can be used to initiate either a *suggested* or an *automatic* palliative care consultation.¹⁴

We retrospectively applied selected Center to Advance Palliative Care criteria to a cohort of children admitted to a cardiac ICU and compared clinical and demographic differences between children in the cohort who received a paediatric palliative care consultation and those who might benefit from a palliative care consult but did not receive one. Our aim was to understand clinical differences and consultation patterns and to identify children who might benefit from palliative care services.

Materials and methods

Study setting

Primary Children's Hospital is a free-standing 289-bed academic children's hospital in Salt Lake City, Utah. The cardiac ICU has 16 beds and treats approximately 400 children undergoing open-heart surgery each year. The Institutional Review Boards at the University of Utah and Primary Children's Hospital approved this study.

The interdisciplinary paediatric palliative care team at Primary Children's Hospital includes board-certified Paediatric Hospice and Palliative Medicine physicians, nurse practitioners, a social worker, a registered nurse, and a chaplain. Any child with a potentially life-limiting medical condition is eligible for a palliative care consultation and licensed medical providers in any hospital unit may place a referral. Our institution does not employ a formal or automatic process for palliative care consultation, rather, it is dependent on a clinician's individual judgement. The patient and family can accept or refuse the consultation. Once a consultation has occurred, the palliative care team remains involved during all subsequent hospitalisations until the condition has resolved, the child has transitioned to medical care for adults, the child dies, or the family no longer wishes to utilise palliative care services.

Center to Advance Palliative Care criteria

The Center to Advance Palliative Care is a national non-profit organisation that provides tools, training, and technical assistance to health care organisations to improve the quality of care for patients and families facing serious illness. Center to Advance Palliative Care has published criteria to identify children with serious illness who would benefit from a specialised palliative care consultation. These criteria may be used to prompt either a *suggested* or an *automatic* consultation based on organ system involvement, frequency or duration of intensive care and hospital length of stay, and decision-making around adoption of new technologies such as extracorporeal membrane oxygenation, ventricular assist device, or organ transplantation.¹⁴

Table 1 lists Center to Advance Palliative Care referral criteria for children with heart disease. We utilised the following Center to Advance Palliative Care suggested criteria: consecutive cardiac ICU length of stay > 14 days and/or ≥ 3 hospitalisations during a 6-month period to determine children in the cardiac ICU eligible for a consultation. We chose these criteria as they are objective, concrete, and easily retrievable from electronic medical records as compared with the automatic criteria that would involve manual review of medical records and contain levels of severity within diagnoses including the words "significant", "severe", "consideration" that can vary from provider to provider.

Table 1. Center to Advance Palliative Care guidelines for PPC consultation in children with heart disease

<i>Automatic</i>	<i>Suggested</i>
Single ventricle physiology	Complex congenital heart disease
Severe pulmonary hypertension	Extracorporeal membrane oxygenation
Down syndrome with significant cardiac abnormality	Severe myocarditis
Cardiomyopathy (hypertrophic or dilated)	≥ 3 hospitalisations in 6 months*
Pulmonary atresia with hypoplastic pulmonary arteries	ICU length of stay >14 days*
Cardiac transplant consideration	
Combination of cardiac diagnosis with underlying neurologic/chromosomal diagnosis	

*Selected criteria to determine eligible population in children admitted to the CICU Adapted from Center to Advance Palliative Care.

Friebert S, Osenga K (2009) Pediatric palliative care referral criteria. Pediatric palliative care referral criteria Center to Advance Palliative Care.

Patient selection

All children (0–21 years old) admitted to the cardiac ICU from January 2014 to June 2017 were screened for inclusion. The eligible cohort consisted of children diagnosed with heart disease during the study period who met the selected Center to Advance Palliative Care criteria described above.

Measurements

We obtained demographic and clinical information from the institutional data warehouse including date of receipt of first paediatric palliative care consultation from the time of the heart diagnosis, pre-natal paediatric palliative care consultation, date of confirmed heart diagnosis, timing of heart disease diagnosis (pre- versus Post-natal diagnosis), treatment, age at first heart surgery, hospital and cardiac ICU length of stay, disease severity measures, and modes and location of death. The date and documentation of the palliative care consultation were verified in the electronic medical records.

Characteristics of children eligible for paediatric palliative care based on the Center to Advance Palliative Care selected criteria who received a paediatric palliative care consultation from the Primary Children's Hospital Palliative Care Team were compared with those who were eligible for but did not receive a consultation.

Disease severity measures

Complex chronic conditions, cumulative hospital and cardiac ICU length of stay, Risk Adjustment for Congenital Heart Surgery, and mortality were used as indicators of disease severity. Children were categorised based on the treatment of their heart disease as surgical, medical, or cardiac catheterisation. If a child had a surgical repair and a cardiac catheterisation, the child was classified as surgical.

The number and type of complex chronic conditions were identified based on codes from the International Classification of Disease version 10 Clinical Modification and as defined by Feudtner and colleagues.¹⁵ The number of complex chronic conditions was identified at two time points: 1) at the end of first hospitalisation and 2) at the end of study period or time of death.

The Risk Adjustment for Congenital Heart Surgery is a classification of surgical procedures into six risk categories from 1 (least complex) to 6 (most complex) used to compare in-hospital mortality for children undergoing surgery for congenital heart disease.¹⁶ We categorised Risk Adjustment for Congenital Heart Surgery groups into 1-2, 3-4, and 5-6. For children with more than one surgery, the highest Risk Adjustment for Congenital Heart Surgery score during the study period was used.

Modes of death were classified into four categories by the care provided at the time of death^{17,18}: 1) *withdrawal of life-sustaining therapies*, defined as discontinuation of mechanical ventilation, blood pressure supporting infusions, and extracorporeal membrane oxygenation, 2) *comfort care*, defined as symptom management in the hospital, hospice, or chronic care facility, 3) *died during cardiopulmonary resuscitation*, defined as patient arrested and underwent *cardiopulmonary resuscitation* without success at home or during hospitalisation, and 4) *unknown*.

Statistical analysis

Descriptive statistics were used to compare demographic and clinical characteristics of children with and without a palliative care consultation. Categorical variables were summarised as counts and percentages and compared using Chi-square tests or Fisher's exact tests as appropriate. Continuous data were described using medians and interquartile ranges and compared using the Mann-Whitney U test. A p value < 0.05 was considered significant. All data were analysed using SAS 9.4 for Windows (SAS Inst. Cary, NC).

Results

Figure 1 shows that 1389 children were admitted to the cardiac ICU during the study period. Of these, 1101 children were excluded because they either did not meet the Center to Advance Palliative Care suggested criteria ($n = 969$) or were diagnosed with heart disease before the start of the study period ($n = 132$). The remaining 288 children were eligible for inclusion in the cohort.

Less than 20% ($n = 48$, 17%) of the cohort received a paediatric palliative care consultation. Table 2 compares the demographic and clinical characteristics of the cohort by consultation status. Overall, both groups were male (60% versus 59%), diagnosed pre-natally (50% versus 49%), neonates at first hospital admission (73% versus 76%), and admitted for surgical treatment (81% versus 96%). Children with a consultation were more likely to receive cardiac catheterisation (17% versus 3%; $p = 0.001$) and were more likely to be older than 1 year of age at first cardiac surgery (13% versus 8%; $p = 0.015$) compared with the non-consulted group. Of the 142 pre-natally diagnosed children, only one received a paediatric palliative care consult during the pre-natal period and 23 received post-natally. The median age of confirmed heart disease diagnosis and first hospitalisation for children in both groups was 1 day. Children who received a consult were nearly 2 months of age at the time of the consultation.

Overall, children in the consulted group experienced higher disease severity compared with the non-consulted group (Table 3). The consulted group had more complex chronic conditions at the end of first hospitalisation (median 3 versus 1; $p < 0.001$) and at end of the study (median 4 versus 2; $p < 0.001$), longer cardiac ICU (median 27 days versus 17 days; $p = 0.001$) and hospital length of stay (median 91 days versus 35 days; $p < 0.001$), and a

six-fold mortality rate (42% versus 7%; $p < 0.001$). When comparing surgical children, the proportion of children within each Risk Adjustment for Congenital Heart Surgery category group was similar between the consulted and non-consulted groups. However, the number of children within the highest surgical risk category group 5-6 had the highest number of children pre-natally diagnosed ($n = 41$, 87%) and the least number of children consulted ($n = 4$, 8%).

Table 4 shows that mortality varied by consultation. The consulted group had a higher median number of complex chronic conditions at the end of first hospitalisation (3 versus 2; $p < 0.007$), longer cumulative hospital length of stay (85 days versus 46 days; $p < 0.027$), received more comfort care at the end of life, and were less likely to die during cardiopulmonary resuscitation compared with the non-consulted group.

Discussion

When applying selected Center to Advance Palliative Care criteria, the number of children eligible for paediatric palliative care consultation treated in a cardiac ICU was significantly higher than the number of children who actually received a consultation. Additionally, most of the eligible children were diagnosed with heart disease pre-natally or soon after birth, but palliative care was not consulted until 2 months of age after a long ICU length of stay, several complex chronic conditions, and high risk of mortality. Our findings suggest potential opportunities for earlier paediatric palliative care involvement in the pre-natal and post-natal period during a cardiac ICU stay.

In our study, less than 20% of eligible children received a palliative care consultation. The majority of children who received a consultation were infants who experienced high disease severity and mortality rate and underwent cardiac catheterisation as a palliative procedure. These findings may be at least partially related to a common misconception that paediatric palliative care services are only useful for end-of-life care, or when all curative efforts have been exhausted when in fact, paediatric palliative care involvement works best when integrated with curative efforts early during the disease trajectory.¹⁹ The presence of complex chronic conditions negatively impacts the child's health care needs, prognosis, and ICU resources¹⁹⁻²¹ and as such, these children would benefit from consultation when these conditions first emerge, prior to a period of crisis. Initiating a palliative care consultation in the midst of a crisis limits the ability of the paediatric palliative care team to build a longitudinal relationship with families throughout the entire illness trajectory and ensure that the families' values, goals of care, and advanced care planning are upheld.²² Palliative care consultation is associated with improved pain control, shorter hospital and intensive care stays, fewer invasive interventions and inpatient deaths.^{18,23}

We found that children with a consultation received comfort care at the end of life and died less during cardiopulmonary resuscitation than non-consulted children suggesting that the families' advanced care goals were met.

Children who did not receive a consultation were often neonates with critical congenital heart disease, many of whom were diagnosed either pre-natally or soon after birth. While the optimal timing for paediatric palliative care consultation in children with heart disease is unknown, several studies and The National Pediatric Cardiology Quality Improvement Collaborative suggest that a consultation during the pre-natal period is warranted for neonates with single ventricle physiology, typically Risk

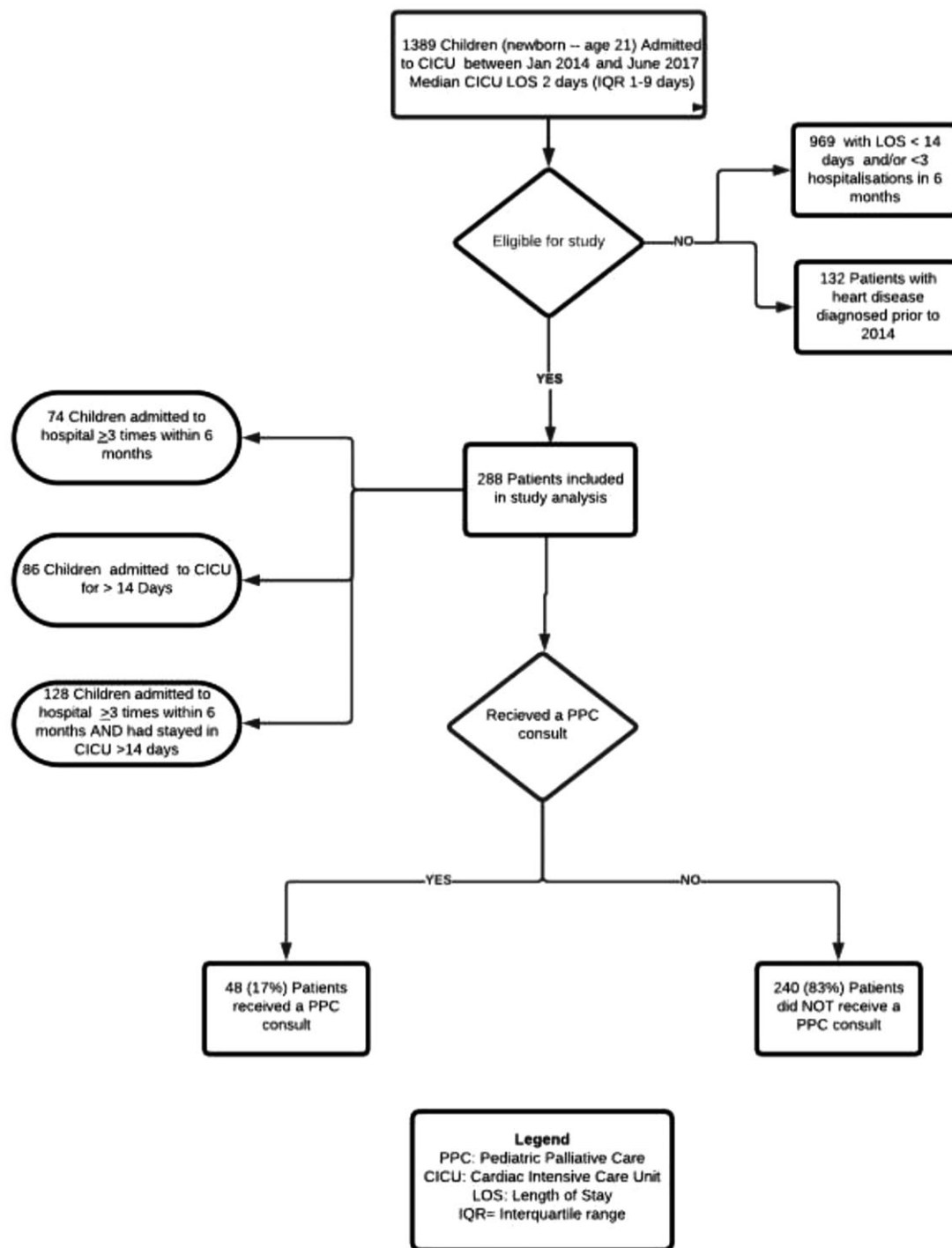


Figure 1. Inclusion and exclusion diagram.

IQR = Interquartile range, CICU = Cardiac Intensive Care Unit, LOS = length of stay, PPC = Paediatric palliative care.

Adjustment for Congenital Heart Surgery 5-6.^{24,25} The pre-natal consult would be followed by the paediatric palliative care team when the child is first admitted to the cardiac intensive care unit. Hancock and colleagues found that paediatric palliative care involvement following birth but just prior to first stage palliative surgery for pre-natally diagnosed single ventricle neonates decreased maternal stress and anxiety.^{24,25} Furthermore, a recent survey found that many health care professionals agreed that pre-natal paediatric palliative care consultation provided at the

time of diagnosis for children with single ventricle heart lesions provides continuity of care and expands the support network for families while decreasing family stress in the post-natal period.²⁵

Different models for paediatric palliative care consultation have been described and include clinician-based (such as ours), parental or nurse prompted, and automatic/triggered consultation based on screening criteria.²⁶⁻³⁰ There is potential to increase palliative care consultation in children in the cardiac ICU by standardising the

Table 2. Demographic and clinical characteristics of Center to Advance Palliative Care eligible children compared by paediatric palliative care consultation

All Children (n = 288)	PPC (+) (n = 48, 17%)	PPC (-) (n = 240, 83%)	P
Sex, n (%)			
Male	29 (60)	141 (59)	0.830
Pre-natal diagnosis, n (%)			
	24 (50)	118 (49)	0.916
Age at confirmed heart diagnosis, median (IQR), days			
	1 d (0 d–49 d)	0 d (0 d–10 d)	0.306
Age at first hospital admission, median (IQR), days			
	1 d (0 d – 45 d)	1 d (0 d – 28 d)	0.469
Age distribution at first hospital admission, N (%)			
< 30 days	35 (73)	182 (76)	
31 days–6 months	8 (17)	32 (13)	
> 6 months–1 year	0	11 (5)	
>1 year–5 years	3 (6)	7 (3)	
>5 years	2 (4)	8 (3)	0.359
Treatment of heart disease n (%)			
Surgical	39 (81)	231 (96)	
Cardiac catheterisation	8 (17)	7 (3)	
Medical	1 (2)	2 (1)	0.001
Age at first surgery, median (IQR) days			
	25 d (6 d–200 d)	13 d (7 d–156 d)	0.551
Age distribution at time of first surgery, N = 270 n (%)			
< 30 days	n = 39	n = 231	
31 days–6 months	21 (54)	135 (59)	
>6 months–1 year	8 (20)	45 (19)	
>1 year	5 (13)	32 (14)	
	5 (13)	19 (8)	0.015
Age at PPC consultation, median IQR, days			
	53 d (26 d–182 d)	n/a	

IQR = Interquartile range; PPC = Paediatric Palliative Care.

screening process using pre-selected criteria that automatically identify children who might benefit from a consultation. In adult ICUs, the use of screening criteria has led to increased palliative care consultation and decreased time to palliative care referral while reducing ICU resource utilisation and improving the family and patient experience.^{30–32} A study in a neonatal intensive care unit using a trigger list with the most severe life-threatening conditions increased paediatric palliative care consultation from 25 to 100%.³³ The screening criteria retrospectively applied in this study suggest that the variability and timing in our hospital for which child gets a paediatric palliative care consultation can be reduced. In addition, the same criteria can facilitate an automated process in the future where children eligible for a consultation can be identified by both the CICU and palliative care providers using the daily census without overwhelming the palliative care service.

Table 3. Disease severity of eligible children compared by receipt of paediatric palliative care consultation

All Children (n = 288)	PPC (+) (n = 48)	PPC (-) (n = 240)	P
Complex chronic conditions			
CCCs at the end of first hospitalisation, median (IQR)	3 (2–4)	1 (1–2)	<0.001
End of study CCCs, median (IQR)	4 (3–6)	2 (1–4)	<0.001
Hospital and CICU LOS			
Total CICU days, median (IQR)	27 (14–54)	17 (10–25)	<0.001
Total hospital days, median (IQR)	91 (58–150)	35 (24–55)	< 0.001
Number of hospitalisations	4 (2–7)	4 (2–5)	0.992
Mortality, n (%)	20 (42)	16 (7)	<0.001
Surgical children only			
	PPC (+) (n = 39)	PPC (-) (n = 231)	
RACHS-1 groups (n) (%)			
1–2	7 (18)	37 (16)	
3–4	25 (64)	138 (60)	
5–6	4 (10)	43 (19)	
Unclassified	3 (8)	13 (5)	0.596
Pre-natal diagnosis by RACHS			
	(n = 18)	(n = 114)	
1–2	3 (17)	10 (9)	
3–4	12 (66)	65 (57)	
5–6	3 (17)	38 (33)	
Unclassified	0 (0)	1 (1)	0.239

CCC = complex chronic condition; CICU = Cardiac Intensive Care Unit; IQR = Interquartile range; LOS = length of stay; PPC = Paediatric palliative care; RACHS = Risk Adjustment for Congenital Heart Surgery.

A recent publication suggests a champion-based model where cardiac ICU-based champions reinforce the paediatric palliative care team by initiating staff training regarding palliative care, implementing quality improvement to find the optimal method and timing for palliative care, and serving as a liaison between the paediatric palliative care and cardiac ICU teams.³⁴ The champion model may provide a starting point for cardiac ICUs with low paediatric palliative care consultation rates and serve as a bridge between a physician-initiated model and the use of a screening criteria model. Regardless of which model or clinical screening criteria are selected, the decision should be tailored to meet the needs of the specific cardiac ICU setting and include stakeholder agreement.²⁷

This study has several limitations. As a single-centre retrospective study, generalisability of our findings is limited. Additionally, we do not know if a family was offered a consultation and refused it. As a result, it is possible that we may have underestimated the percentage of children who received a palliative care referral. We collected data from an administrative database, and there may be under or over-reporting of complex chronic conditions related to

Table 4. Characteristics of children deaths compared by paediatric palliative care consultation

Children deaths (n = 36)	PPC (+) (n = 20)	PPC (-) (n = 16)	P
Age at time of death			
Age in days, median (IQR)	146 (71–225)	138 (53–197)	0.811
Complex chronic conditions			
CCCs at the end of first hospitalisation, median (IQR)	3 (2–5)	2 (1–2)	0.007
CCCs at time of death, median (IQR)	3 (2–5)	3 (1–4)	0.115
Hospital and CICU LOS			
CICU LOS in days, median (IQR)	43 (21–56)	23 (17–45)	0.340
Hospital LOS in days, median (IQR)	85 (58–118)	46 (22–92)	0.027
Location of death, n (%)			
Intensive care unit	15 (75)	12 (75)	
Home on hospice	3 (15)	0 (0)	
Hospital, or LTAC not ICU	2 (10)	3 (19)	0.286
Unknown	0 (0)	1 (6)	
Modes of death, n (%)			
Withdrawal of life-sustaining therapies	14 (70)	10 (63)	
Comfort care	4 (20)	0 (0)	
Died during resuscitation	2 (10)	5 (31)	0.078
Unknown	0 (0)	1 (6)	
Days between PPC and death, median IQR	83 (21–199)	n/a	
Distribution of days between PPC and death, n (%)			
0 days	2 (10)	n/a	
1–9 days	1 (5)	n/a	
10–30 days	3 (15)	n/a	
>30 days	14 (70)	n/a	

CCC = complex chronic condition; CICU = Cardiac Intensive Care Unit; ICU = intensive care unit; IQR = Interquartile range; LOS = length of stay; LTAC = long term acute care; PPC = Paediatric palliative care;

possible misclassifications in the International Classification of Disease version 10 Clinical Modification coding.

Conclusion

We found a low rate of paediatric palliative care consultation in children admitted to a cardiac ICU who met specific Center to Advanced Palliative Care criteria. When paediatric palliative care consultation did occur, it was in the context of medical complexity and high risk of mortality. Additionally, the consultation was rare in neonates with critical congenital heart disease despite pre-natal diagnosis or diagnosis soon after birth. Implementation of screening criteria may help identify and increase paediatric palliative care consultation in the cardiac ICU in a more timely and equitable manner. The study illustrates the need for collaboration by all stakeholders including intensivists, cardiothoracic surgeons, cardiologists, and the palliative care team to augment patient care and give children and families the opportunity to receive palliative care services earlier, while managing limited palliative care resources.

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